



## "I Wake Up for MY Dream!" Personal Futures Planning Circles of Support, MAPS and PATH

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Individuals with an autism spectrum disorder need support for their future success. They need to start as early as possible to establish paths that can lead to more successful school years and adulthood. It is never too late to begin to plan. Futures Planning can begin to open opportunities in the school and in the community for individuals with autism spectrum disorders. It can build a support network for both the family and the individual him or herself and can lead to the establishment of important relationships.

There are three specific tools many people with and without disabilities have used to create the support and vision for their futures. The tools are Circles of Support (Friends), MAPS (Making Action Plans) and PATH (Planning Alternative Tomorrows with Hope). Each tool has a specific purpose but all are about creating positive futures. The most important and unique aspect of these tools is that the person with the disability is at the heart of each tool.

*"The person is first and foremost—the heart of the matter. In order to actually realize what any person needs or wants, nothing is more important than genuinely listening to that person. We must not 'presume' wants or needs; rather we must help an individual make choices and then facilitate the journey towards those goals. It means giving up control and learning how to listen. It means being non-judgmental, but creating a positive supportive framework within which there is a balance of safety and responsibility, all focused by genuine selection of direction by the person. Our planning for others needs to mature to 'planning with'. It always needs to be within the framework of what a person wants for his or her life. It is vital to remember that it is his or her life. Striking this balance is not **ALWAYS** easy. In fact, it is hardly ever easy, but it is always right. There are no guarantees that people will get what they want, but at least we will have done our best and there is integrity in the route we have tried. It is honest. There is one additional reason to take this route—very often, it works!" (Forest & Pearpoint, 1998).*

Let us illustrate this process by telling the story of George Howard. " George was diagnosed at age two with Pervasive Developmental Disability-Not Otherwise Specified (PDD-NOS) after a history of ear infections and the loss of language. He presented with severe language delays and behaviors typically associated with autism. George engaged in repetitive play usually related to obsessive interests in specific playthings. He had, at times, uncontrollable frustration that took the form of screaming. He was not injurious to himself or others, but he had completely retreated into his world of cartoon characters and videos. He also demonstrated tactile defensiveness and auditory sensitivity. The most severe was his auditory sensitivity. He would hide in corners in a fetal position and hold his ears. Rarely could he be comforted. He had virtually no functional language and used his hand to direct people to his needs. It was clear he needed intensive intervention. George began with private occupational therapy and speech therapy. He also received Auditory Integration and Sensory Integration. At three, he was enrolled in both the special education preschool program in the mornings for structure and a private community-based preschool program in the afternoons for social exposure. He attended both schools over a period of three and one half years. During that time, he repeated Auditory Integration Therapy two more times and worked on a computer-based language-processing program. His private therapists worked extensively with him in the clinic as well as in other settings to help him cope with his world" (Cathy Luerssen, Mom).

George was in preschool when his teacher, Diane, heard about Personal Futures Planning. She talked with Cathy and Bill Howard, George's parents about this process. After talking to a consultant from the Indiana Resource Center for Autism who told them that these planning tools take time and commitment, the family decided to move forward with the process. They believed that in order for George to be successful in school and later in his life within the community, they needed to begin right away. They also knew they could not do it alone. First, they developed their Circle of Support also known as Circle of Friends.

Creating a Circle of Support/Friends takes thoughtful planning and organization. It is not a process that is slapped together in haste because it is a time when friends gather to help plan a future for someone they care about. Circle of Friends (Support) is a group of people who meet on a regular basis to support the focus person to meet his or her personal dreams and goals. The Circle members should be people who are dedicated to the focus person.

It can include people who are professionals in the person's life. A Circle is not associated with any agency or school, but instead is focused on the association with a specific individual. Each Circle member is an equal with power to share ideas, listen to others, voice concerns freely, and work together to help improve the quality of life for the focus person. Members are not paid to be participants in the Circle. Membership in any Circle is voluntary. They are there because they care!

Prior to sending invitations to potential Circle members, the Howard family had to choose a location for the meeting, set the time, establish an agenda for the meeting, and find someone to facilitate the initial meeting. After initial decisions had been made, the invitation process started. As stated, George, the focus person, is ultimately in charge. Since he was too young (5) to determine whom to invite to his first Circle meeting, his parents made a list of people who they felt believed in George and could commit to the process. Their list included family members, private therapists, family friends, and school personnel (e.g., teachers, preschool administrator, therapists, paraeducators). The invitations were sent and the Circle Meeting started to become a reality.

First Circle meetings help the group gain a focus. There is always a facilitator for Circle meetings to help maintain the focus of the group as the meeting progresses. Usually, the facilitator meets with the focus person ahead of time to clarify the person's goals and potential obstacles. At the meeting, the Facilitator can share those dreams with the group and then begin the process of brainstorming the needed supports.

For their first Circle meeting, the Howards decided to do a MAP to help begin the process of creating a positive future for George as he entered kindergarten. They asked IRCA staff to facilitate this process.

"MAP is a process which gathers information and then utilizes that information to develop a plan of action for a person. It is based on dreaming and listening. The aim of a MAP is to move away from a person's nightmares and to do everything possible to move towards their dreams." (Forest & Pearpoint, 1998). When the Circle gathers to do a MAP, the facilitator helps the group focus on the capacity, gifts, and talents of the individual. A primary goal is to help plan for the successful involvement of the student for not only academic reasons, but also for the social aspects of school. Typical peers who are interested are included for their unique contributions and abilities to help the process. This process helps the group focus on the value of developing social relationships as well as inclusion in general education classes. The facilitator guides the Circle through a series of questions that begin to shape the plan of action.

The Howards were aware that the facilitator would be asking questions that could sometimes become quite personal and emotional. They knew they had created a safe environment that made sharing easier for them. The last questions, which are answered by the Circle members, focused on George's unique strengths and interests and also helped start the creation of strategies to overcome obstacles to help George reach his dreams. The questions are:

1. What is George's history? Family members who know George best were asked to talk about George's life history, including some of the milestones for him.
2. What is your dream for George as an adult? The Circle helped the family to develop a vision for George's future; what they truly want for him. It forced them to look beyond the present and dream for him and his family.
3. What is your nightmare? The most difficult question the Howard family had to answer. They identified the situations that the Circle members would work very hard to keep from happening. Like most families, one aspect of the nightmare was that George would be alone in this world.
4. Who is George? All Circle members contributed by sharing words they would use to describe George. There were no right or wrong answers because each person has a different relationship with George.
5. What are George's strengths, gifts, and talents? George has many gifts. Instead of focusing on the challenges, this question allowed everyone to share what they believe George can do, what he likes to do and can do well.
6. What are George's needs? From their unique perspectives, Circle members revealed what they felt George would need to begin to achieve the dream.
7. What would George's ideal day at school look like? What must be done to make it happen? This process was the beginning of helping George become included at school. This question outlined a typical day and then moved forward into ways to assist George to be more included based on his needs and his gifts. It identified those supports he may need in each situation.

The Circle, as a collective group, answered the final question in a very thoughtful manner. The description of George's potential day helped set the stage for the beginning of his successful involvement at school.

At the end of the meeting, a decision was made about when the next meeting would take place. Setting the next meeting was an excellent way to assure that the majority of people would be there instead of calling a meeting spontaneously.

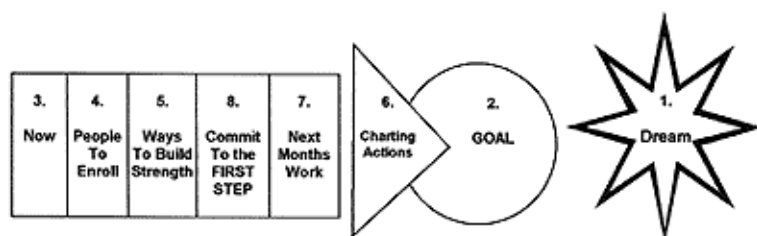
As George moved into Kindergarten, the Circle of Support/Friends continued to meet on a regular basis to discuss his successes and challenges. It was decided to meet quarterly, appoint facilitators, and create a standard agenda for the Circle meetings. The Circle created a simple agenda: Celebrations, Concerns, Plan of Action, Action Assignments, Next Meeting Date, and Potential Agenda Items. It was understood that membership continued to be voluntary but everyone was an equal and valued member of the Circle. If issues surfaced that needed immediate Circle support, anyone could call a Circle meeting. To help alleviate emergency situations, the school staff met regularly to be sure things were clear and moving forward. These were not circle meetings, but school staffings focused on strictly school issues. Personal futures planning involves more than school; it is about the person's life!

The Howard Circle had the opportunity to be involved in one more aspect of personal futures planning for George during an IRCA summer institute. This was the summer before George would enter 1st grade. They were asked if they would be willing to have a PATH created for George as part of a demonstration. They agreed. The entire Circle did not attend, but his mother, father, brother, preschool teachers, paraeducator, and first grade teacher did participate in the PATH process.

## PATH

According to Pearpoint and Forest, "PATH is an even sharper edged tool than MAP. It is a series of eight structured questions that must be asked in a particular order. A more detailed plan of action emerges at the conclusion of a PATH meeting." (Forest & Pearpoint, 1998). Two trained facilitators are actively involved. One asks the questions related to the steps and guides the discussion, while the other creates the PATH itself through drawing and words. The eight steps in PATH are:

1. Touching the Dream—the North Star
2. Setting the Goal
3. Grounding in the Now
4. Identifying People to Enroll
5. Recognizing Ways to Build Strengths
6. Charting Action for the Next Few Months
7. Planning the Next Months Work
8. Committing to the First Step



In the first step of George's PATH, the Howards had to define their dream for George; his NORTH STAR. It was important for the Circle to allow themselves to be free to see George's possible future without the constraints that had been there. It was up to the facilitator to believe in the dream and allow everyone to dream freely. This became the driving force of George's PATH and is the force behind any PATH. A question used to help the Circle begin thinking about the North Star was "What do you see happening in George's life in the future?"

The Circle members each took a turn in sharing their dream for George. His North Star looked wonderful as they all spoke. In the future, the dreams for George included the following:

- George feels valued and happy!
- He is racing and playing!
- There is growing independence and contributions by George.
- He holds on to his creativity with the support of his Circle of Friends.
- He has strength and friendship on his long journey.
- His family includes: Mom, Dad, Patrick, Miss Patrice, Grandma, Grandpa, and Jason.
- He has lifetime intimate friendships.
- Everyone has come through when we needed help.
- Inclusion, welcomes everyone learning to speak a different language. Differences are seen as positive gifts.
- He has a faith in God.
- We're drawn out of 'privacy' into a world of friendship, knowledge, laughter, hope, and fun with schools, neighbors, and friend.
- People see his strengths and gifts.
- George said, "I wake up for my dream every day!"

After George's Dream had been designed, setting the Goal was the next step. What would the goals be to help those dreams become a reality? These goals would be set for six months, a year, or two years in the future. They are what Forest and Pearpoint call the 'positive and possible' future. The facilitators helped the Circle be creative in setting goals and also in thinking about the goals as if they had already happened. This kept the Circle thinking of things that were positive and possible for George. Their Goal date was June of 2000.

For George and his Circle they had many ideas for what would be the positive and possible Goals. Everyone contributed his or her outlook for George's future at school and in the community. By June 2000, the following goals would be achieved:

- Everyone is 'on board' at school.
- We meet every two weeks in the library and share ideas and muffins!
- George visits my son Derek at our house.
- We got together in August 1999 ...had a big party!
- We smell fresh cut grass, strawberries, blueberry muffins, crayons (George)
- We solved practical problems of lighting, sounds, and surfaces.
- As George's teacher, I spent my time re-learning, adapting, and changing.
- George has been able to move with the other kids from task to task, easily and happily.
- Teachers were flexible...discovered ways to include George
- Other kids are enjoying playing with George, baseball, play dates.
- We are feeling great!
- Other teachers ... 2nd grade teachers were involved in meetings, felt great about George coming into her class.
- George helped other kids with computers ...strong connections came about.
- Mom said I am hearing people's changed attitudes.
- George says I met people. . . School was good on Wednesday.

After discussing the future by dreaming and goal setting, the Circle begins to shift its focus to today or NOW. This step helps the Circle describe what it is like now, today for the individual and the Circle. It is not a judgment time, just a snapshot of life today. This involves the names of people involved and the general feelings they are experiencing with regard to George and his PATH. George had different people involved in his first formal PATH, his family, past and present teachers and therapists, and his classroom assistant. Their feelings ranged from "hopeful-so much work to be done" to "anxious to help get started." The rest of the PATH involves what it takes to get from the 'now' to the 'dream'.

The fourth question: Whom do we need to enroll to achieve the goal? The Circle cannot do it alone and may need to ask for the help of specific outside resources to support the PATH. In George's situation, those identified to enroll were others in the school. The new principal, art and gym teachers, occupational and physical therapists, speech and language clinician, other building teachers, other parents, the 'recess aides', and other kids were needed to help George reach his dreams. The people already in the Circle made the commitment to talk to others on this list about the Circle process and specifically, how they could help George.

How can the group become stronger and more potent in its movement toward the dream is the next step along the PATH. The question becomes: "What do we need to do as a Circle in order to be strong enough to reach the goal and keep moving forward? And, what does each person have to do to be strong enough to be able to make their contribution?" There are many areas to continually strengthen such as open, honest communication among Circle members, learning from one another, accessing outside resources, and continually listening to the individual. The general ideas that George's Circle decided upon were: continuous meetings, a connection with last years teachers and aides, expressing our appreciations, and involving other staff and kids. These were the aspects they had decided would help keep them believing and moving toward the desired goals.

Step six involves thinking ahead, perhaps three months. Here the facilitator must guide the Circle members to once again envision things that have 'happened already' toward the dream and goal. The best way to do this is to pick a clear element of the Goal and think of what has happened already. Getting this thinking started is the

hardest part, once participants understand it is much easier to continue. For George, this step in the PATH involved thinking about things that could happen in first grade.

Step seven takes a step backwards from step six. This step is actually planning the next MONTH'S work. Here, Circle members consider very specific questions to guide this step. For George, this step was set for the month he was to start first grade.

Finally the last step in the PATH is really the first step the Circle members take toward the Goal!! In this step, each Circle member states what he or she will specifically do before the next meeting or month to ensure that the Circle moves toward the Dream. The Facilitator can ask what can be done by tomorrow or next week to get the participants started.

In George's Circle, those at his PATH each stated what their first steps would be. Those steps as stated were:

- "I'll look for children who might be especially good candidates for connections.
- "I'll talk with Cathy."
- "I'll set up a calendar."
- "I'll think about how to create a great classroom atmosphere."
- "I'll call Patrice and share ideas."
- "I'll answer any questions."
- "I'll revisit written notes for ideas. I'll list and contact parents of kids who would be interested."
- "I'll spend some time with George this evening."
- And George said, "I'm going to do some reading."

Each person set a goal for him or herself and stated it aloud. It was important for everyone to understand that the Circle members who support the PATH are in an interdependent process. This means everyone needs to do their part and support each other to make the PATH work. It is the dedication to the individual and the PATH that can help make the Dream a reality!

Each of the Personal Futures Planning Tools can only work well if they are understood and the facilitators keep the Circle on track. It is crucial that the individual remains the heart of the matter. The person's dream and words must drive the Dream. Every effort must be made to 'hear' that person's voice, whatever it may be. For some individuals, other forms of communication may be necessary, but the Circle should "learn to listen" differently if needed. Trust and confidentiality are also crucial because much of the information shared by the Circle can become very personal. It must be safe for all members to share their feelings or concerns with the entire Circle without fear of judgment or bias. If it is not safe, the Circle will be in danger of splits and lose some of its power.

Finally, this is NOT a quick fix; it does NOT take the place of an IEP. It is a long-term plan for life. With commitment and dedication from a Circle, an individual with an autism spectrum disorder can achieve a great deal if their dreams are recognized and everyone works together to seek positive and possible goals for their future. An improved quality of life and living is what everyone wants and what better way to do it than with a Circle of Friends helping along the PATH!!

An update on George and his Circle of Friends proves how successful this process can be. George will be entering 4th grade. He has been completely and successfully included since Kindergarten. He has language that he can use very functionally to answer questions, ask for things, read in class, and greet and talk to people. He is doing well in school and making high marks in his classes. His screaming is fairly well gone. He does have an occasional vocal outburst in class, but it is not prolonged. Sometimes noise is still too loud for him and he may use his vocalizations to drown out the painful noise. He has friends who seek him out at school and with whom he plays with at his home or at theirs on a regular basis. Each year his upcoming teacher joins the Circle and his 'old' teachers just

don't seem to leave. His Circle continues to grow and now includes eight of his peers and their parents. Meetings are quarterly at his former Preschool and last two hours. They are productive, positive, and continue to provide George, but also his family, friends, and others who support him with a source of joy and inspiration to believe that Dreams do come true.

## Reference

Forest, M., & Pearpoint, J. (1998). *Life is either a daring adventure or nothing at all.* Toronto, Canada: Geneva Centre for Autism International Symposium Paper.

Pearpoint, J., Forest, M., & O'Brien, J. (1993). *PATH: planning possible positive futures.* Toronto, Canada: Inclusion Press.

## Video and On-Line Resources

*PATH training video: introduction to PATH.* Toronto, Canada: Inclusion Press.

*Millers Map: Intro to MAP process.* Toronto, Canada: Inclusion Press. <http://www.inclusionpress.com/>: website that includes ordering information on videos and books mentioned above.

## Other Resources

Snow, J. (1994). *What's really worth doing and how to do it.* Toronto, Canada: Inclusion Press.

Flavey, M., Forest, M., Pearpoint, J., & Rosenberg, J. (1993). *All my life's a circle.* Toronto, Canada: Inclusion Press.

Mount, B., & Zwernik, K. (1988). *It's never too early it's never too late.* St. Paul, MN: Metropolitan Council, Minnesota Governor's Planning Council.

Mount, B., Beeman, P., & Ducharme, G. (1988). *What we are learning about circles of support.* Manchester, CT: Communitas, Inc.

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